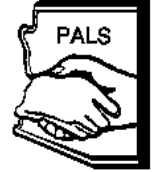




## Parent Information Network



### **A Native American Mother's Journey** **It was the best of times; it was the worst of times** *by Monica Polacca-Fulgham*

It was in 1985 that I was told my daughter Amber, who was then 6 months old, had cerebral palsy. This was a devastating moment in my life. I vaguely remember the details surrounding that time but, I know that it was a moment that changed my life forever. As a mother I had sensed some differences in her development. She seemed to be having difficulty doing the basic skills that most children that age do. I had taken her to regularly scheduled appointments at the well baby clinic and the medical staff requested additional tests and screenings. That was when it all began.

I had absolutely no understanding of what the doctors and service providers were telling me. I sometimes pretended I knew exactly what they were saying but, I had no idea. It seemed as though I was numb and non-feeling. I was practically led through this process by the kind service providers and hospital staff. I remember trying to convince myself that this was not my child that they were talking about. It certainly did not sound like the Amber I knew. As far as I was concerned, I had a perfect child.

Shortly after I had absorbed this news about my daughter's diagnosis, I fell into a mild depression of my own. I don't know that my family even took notice to this, but I believe it was the only way I was able to deal with this new situation. I was going through the motions you could say. I felt sorry for myself and for my child. I felt angry, afraid, and alone. I cried a lot and not just on the outside, but on the inside too. I remember asking God over and over again "Why me?" "Why Amber?"

Then all the other questions started coming... questions like "What kind of a life is she going to have?" "Can she go to school?" "Will she be able to run or even walk?" "Will she be teased by the other children?"

I cannot tell you how long this grieving lasted, but I know it was necessary for me to get out all the pain I was carrying in my heart.

My family was very supportive. Being that I am a Native American Indian woman, I have sought guidance and help from our Native American Medicine people. My grandpa told me that prayer was powerful medicine and that it was to be the way to finding my answers. He was right. I soon realized that Amber was always the perfect child I saw her as. She was a special gift that was given to me to live and nurture. I also realized that I was a special gift that was to be shared with her as well. She was to be my partner in this journey and I had never been alone. We had each other and it was going to be a journey that we would embrace together.

I was a single mother who had lots of learning to do and fast. I don't recall the exact order that the many services were provided. I know that it was the wonderful service providers that held my hand and guided me through the system. I was referred to the numerous programs that were available and guided through the process. This is why I know that networking and collaboration between organizations and programs is a must. This effort brings families to the services that are greatly needed. It was what kept Amber from falling through the cracks.

If it were not for these individuals I would not have been able to find the appropriate services for my daughter.

Amber would not have had the opportunity to receive early intervention services nor would she have learned to develop the skills she needed to enter public school.

This is where the challenges took a change in an unfamiliar direction. Not only did we have to be strong through the surgeries, but we had to find the strength and knowledge to make it through the education process. I was terrified to send my daughter to a public school with other children, children that may or may not accept her and school staff that were not familiar with her disability. She, on the other hand, was excited and thrilled with the idea of going to a school that had a big playground, riding the yellow school bus, and making lots of new friends. It still pleases me to see the strength and belief that she has in herself. When I felt myself losing it and feeling the fear creep back into my heart, I would turn and look at her and remind myself that this was not about me, it was still about her. It was still about her dreams and her future. I put it all in God's hands and prayed that everything would work out. I remember the feeling of helplessness from time to time, and recall telling myself I had to snap out of it and focus on the positive of every situation.

I read everything I could get my hands on. Whether it was on Cerebral Palsy, educating children with disabilities, or being an effective parent for my child. I realized that I was the only voice that Amber had, at least until she would learn to speak for herself. I had to learn to express myself in productive ways so that Amber would be able to receive the appropriate services to the fullest extent possible. I had to learn to work together with the teachers, school staff, and therapists.

Working together and building relationships has been beneficial for the school, Amber, and me. I have found that building good rapport with everyone

involved in Amber's education has been the best experience for me. In doing so, I had to learn to be flexible, patient, and understanding. I have also learned of the fears that educators and school staff may have in teaching children with disabilities. Every new school year I become the teacher to the teachers and school staff. This is necessary because they are not familiar with my child nor are they aware of Amber's interests and aptitudes.

Amber has always shown a strong interest in science and the natural world around her. As her mother, I have made it a point to have her involved in as many activities as possible. Amber has been an active Girl Scout for 8 years. She has been a part of community youth activities and summer youth camps. Amber is the only girl in her school district with a disability that has run for Tse Ho Tso Middle School Princess Pageant twice. She came in 3<sup>rd</sup> runner up the first year and 1<sup>st</sup> runner up the second year. While participating in the pageant, she used her lap top computer as a form of assistance in her talent. She has also placed 1<sup>st</sup> in two state science fairs for Native American Indian students and attends school dances and functions quite often. She is a typical teenage girl with lots of hopes and dreams for her future. I am so proud of her. She has been my teacher in life and she has taught me many valuable lessons. I have become a strong confident woman because of my daughter.

The journey has been an experience I will never forget. Part of the result of this journey is that Amber is still growing and learning as am I. Eventually she will take over as her own advocate and become the Pediatrician she desires to be.